

### **Information for healthcare providers**

Your patient has contacted the Undiagnosed Diseases Network (UDN) about participating in this research study. Patient participants will be evaluated using the unique combination of scientific and medical expertise and resources. Participants must have a condition that has not been diagnosed following a thorough medical evaluation. More information about the UDN can be found here: <https://undiagnosed.hms.harvard.edu>.

If your patient decides to apply for this study, he/she will need to answer a series of brief questions through our application Gateway (<https://gateway.undiagnosed.hms.harvard.edu>) related to the following:

- Contact information
- Demographic information
- Primary licensed healthcare provider information (name, address, phone, FAX, email)
- Brief medical history questions
- Previous evaluations
- Travel limitations

A study recommendation letter from a primary licensed healthcare provider is also necessary in order to submit the online application to the UDN. The patient will be asked to upload this letter to the online application. The study recommendation letter must include:

- A summary of the applicant's medical problems
- Date when symptoms were first noticed
- Previous diagnoses
- History of evaluations and testing
- History of treatments and medications
- Current medications
- Family history
- Healthcare provider's diagnostic impressions
- For pediatric patients: prenatal and birth history

After an application is submitted, it is then sent to one of the UDN clinical sites to review. The UDN clinical sites typically contact applicants within one month of application submission to request additional information, such as:

- Medical records
- Laboratory studies
- MRI, X-ray, or CT images (can be sent on CD)
- Photographs or videos
- Pathology slides and reports
- For pediatric patients: growth curves

In order to help with the application review process, the patient can begin to collect these records now. However, medical records should not be sent until specific instructions to do so are received from a UDN clinical site.



After all of the necessary information is received by a UDN clinical site, it typically takes 6-8 weeks for the network to make a decision whether to accept an applicant.

If your patient's case is accepted for UDN evaluation, the UDN will provide information from the evaluation to you and to your patient. You will be responsible for your patient's follow up medical care.

Thank you for considering this opportunity to consult with the UDN on your patient. We appreciate your commitment to providing the best possible care for your patients in ways that help advance medical knowledge and discovery.